

**STATEMENT OF BETH Y. KARLAN, MD**

**BEFORE THE SUBCOMMITTEE ON CRIMINAL JUSTICE, DRUG POLICY AND  
HUMAN RESOURCES**

**SEPTEMBER 7, 2005**

Mr. Chairman, Ranking Member and members of the subcommittee, thank you for inviting me to testify at today's hearing. I am honored to be here and heartened by the interest of the subcommittee in this important issue.

My name is Dr. Beth Karlan, and I am the President of the Society of Gynecologic Oncologists. I practice medicine at Cedars-Sinai Medical Center and the Oschin Cancer Institute in Los Angeles, California, where I am the Director of the Women's Cancer Research Institute, the Division of Gynecologic Oncology and the Gilda Radner Hereditary Cancer Detection Program. I am also Professor of Obstetrics and Gynecology at the University of California, Los Angeles' (UCLA) Geffen School of Medicine.

The Society of Gynecologic Oncologists (SGO) is a national surgical specialty society of physicians. Our membership is trained in the comprehensive management of women with reproductive cancers. Our purpose is to improve the care of women with gynecologic cancer by encouraging research and disseminating knowledge. Our overall effort is focused on raising the standards of practice in the prevention and treatment of gynecologic malignancies through cooperation with other organizations interested in women's health care, oncology and related fields. SGO's members make the Society the leading organization of gynecologic oncologists in the United States. As gynecologic oncologists, we are women's cancer specialists who have received an additional three-four years of intensive post-graduate medical training in the comprehensive treatment of gynecologic cancers, including cancers of the ovary, endometrium, cervix, vulva and vagina.

At the outset, I wish to clearly state my belief that Congress can take action that will, in the immediate future, save thousands of women from dying from these cancers. Today, in the United States, one woman will be diagnosed with a gynecologic cancer every seven minutes. That's over 200 women today and close to 80,000 this year. Over one-third of these women will die unnecessarily. Early education and prevention, as well as effective screening, could save many of these lives. Sadly, too many women are unaware of the early symptoms of gynecologic cancer. If detected early, the vast majority of these cancers are curable. Without fact-based information, many women are unable to ask the right questions of their physicians -- questions that can save their lives. Through the establishment of a federal program, women could receive education about the early warning signs for and the effectiveness of early detection of gynecologic cancer.

Arming women with this critical knowledge is the purpose of H. R. 1245, the Gynecologic Cancer Education and Awareness Act of 2005 -- commonly referred to as "Johanna's Law." Passage of "Johanna's Law," which I will describe in more detail, could immediately prevent needless deaths from these cancers.

From my vantage point as a surgeon specializing in the treatment of gynecologic cancers, and as president of SGO, I can assure this subcommittee that today's hearing performs a critical public service. The paucity of public discussion and attention about gynecologic cancers is literally killing

thousands of women in our country because they do not know, nor do they understand, their risks of developing a gynecologic cancer. I could sit here and recount hundreds of first person stories of women who came into my care too late, and did not know the warning signs that their own bodies sent to alert them to the presence of cancer. Had they known what to watch for and how to listen to their bodies, we could have intervened earlier and saved their lives.

To better illustrate the job I believe we must do, I like to draw a parallel between gynecologic cancer and breast cancer. I believe we are all old enough to remember when little was known about breast cancer, screening was in its infancy, and a late stage diagnosis often meant physically deforming surgery, scorching radiation therapy, and many times death. In 20 years we have revolutionized breast cancer care and survival by advocating for heightened awareness, improved screening and novel treatments. Open discussions about risks, early detection and intervention have saved thousands of lives. It is our firm belief, and the intention of this legislation, that we must achieve the same outcome for gynecologic cancers, and create an environment where gynecologic anatomy can be named and visualized just as comfortably as the anatomy of the breast.

We don't come to you with only a vision, we have data to support our case for this legislation. Today, SGO's Foundation, the Gynecologic Cancer Foundation (GCF) and Research!America released the results of a poll of 800 women across America that asked women about their knowledge of gynecologic cancers. The poll report is submitted as part of my testimony.

Here are just a few of the astonishing statistics:

- 47 percent of women surveyed could not name one symptom of gynecologic cancers, not one!
- 45 percent of women surveyed were not aware of any personal risk factors that increased their chance of developing a gynecologic cancer.
- Almost 60 percent of women surveyed could not name one step they could take to decrease their personal risk of developing a gynecologic cancer.

Clearly this data suggests that with even a modest improvement in outreach and education, we can save lives and precious healthcare resources, and improve the health of our nation's women. This legislation will accomplish that – through education of both women and their health care providers.

To help you better understand each of the gynecologic cancers and our opportunity to improve survival for every one of them, I have submitted for the congressional record a copy of the 2005 State of the State of Gynecologic Cancers. Each year at the beginning of September, Gynecologic Cancer Awareness Month, SGO and GCF publish this report to the women of America describing each gynecologic cancer---their risks, symptoms, incidence rates, and most importantly, the advances made during the past year. For the purposes of my testimony, I will briefly discuss the three most common female reproductive cancers -- cervical, ovarian and uterine cancer and invite you to consult the report for information about the less common gynecologic cancers.

Cervical cancer begins in the cervix, the lowest portion of the uterus or womb that opens into the vagina. It results when abnormal cellular changes go undetected and invade the underlying cervical tissue. Cervical cancer is the only gynecological cancer that can be prevented by regular Pap smear screening, yet over half of the women dying from cervical cancer in the United States have never had

a Pap smear. Cancer of the cervix usually affects women between the ages of 30 and 55 but has been found as early as the teenaged years. This year an estimated 10,370 cases of invasive cervical cancer are expected to be diagnosed and result in approximately 3,710 deaths. Because this cancer is totally preventable, each one of these deaths is, sadly, an unnecessary death.

Ovarian cancer usually arises from the cells on the surface of the ovary and can be extremely difficult to detect. But it is not a silent disease. Recent studies demonstrate that approximately 40 percent of women with ovarian cancer saw their physicians 4-12 months before the diagnosis was made and complained of symptoms including abdominal pain, bloating and gastrointestinal distress. As you will hear from other witnesses on this panel, this delay in diagnosis often makes it too late for medical intervention to be effective. Ovarian cancer ranks fourth in cancer deaths among women and causes more deaths than all the other cancers of the female reproductive tract combined. It is estimated that there will be more than 22,220 new cases diagnosed this year and approximately 16,210 women will die from this disease. Knowledge of the symptoms of this cancer can literally save women's lives. Johanna's story makes this point so poignantly clear.

Uterine cancer usually begins in the lining of the uterus, or endometrium, when cells in the lining grow out of control and invade the muscle of the uterus. It most frequently occurs in women around perimenopause or in the postmenopausal years but may occur in younger women as well. Cancer of the endometrium is the most common of the female reproductive cancers. This year it is estimated there will be 40,880 new cases of uterine cancer diagnosed, and that this will result in 7,310 deaths. The GCF-Research!America poll found that women over 65 do not feel that they are at risk of developing a gynecologic cancer, especially when compared with women 35-44 years of age. Again, we must change this number. For in the case of uterine cancer and ovarian cancer, it is these postmenopausal women who are at the greatest risk.

We have made enormous strides in identifying the risk factors and causes of these cancers, including hereditary, environmental, and biological contributors. In the past 10 years our identification of the genes responsible for two hereditary gynecologic cancer syndromes, familial breast-ovarian cancer syndrome and hereditary non-polyposis colorectal cancer syndrome (HNPCC), has contributed greatly to our ability to detect a woman's risk for developing a gynecologic cancer.

Women who are part of the familial breast-ovarian cancer syndrome have inherited a deleterious mutation in either the BRCA1 or BRCA2 genes, which places them at much greater risk for breast and ovarian cancer. On average a woman has a 13 percent risk of developing breast cancer and a 1.8 percent risk of developing ovarian cancer. Women with these BRCA1 or BRCA2 gene mutations have an almost 90 percent risk of developing breast cancer and a 15-40 percent chance of developing ovarian cancer. HNPCC is a cancer family syndrome due to inherited genetic mutations in a different group of genes and results in a predisposition to cancers of the colon, endometrium and ovary. For women with HNPCC syndrome, the lifetime risk of ovarian cancer and endometrial cancer is approximately 10 percent and 40-60 percent, respectively.

Mr. Chairman, we clearly need to know more about why all cancers, including gynecologic cancer, develop and how to detect them early and treat them effectively. But what we already know about gynecologic cancers is significant. We know that some people are at enhanced risk of developing such cancers and, perhaps most critically, that early detection vastly increases the odds of prolonged survival and cure for all of these cancers. One of our biggest problems is that we have not been able

to effectively communicate these facts to the vast majority of the women in our country. And the results of the GCF-Research!America poll dramatically illustrate this point.

You will undoubtedly hear from witnesses today about their personal experiences, as well as the experiences of their loved ones, in discovering and treating their cancers. As I mentioned earlier, in my role as a physician I often see tragic stories that did not have to end tragically -- lives lost that could have been saved with more timely interventions and treatment. Congress' commitment to expanding the boundaries of medical research has been a vital weapon in our war against gynecologic cancer. However, all the treatments in the world will not work if women do not know when, where and how to seek them.

Representatives Issa, Levin, Granger and DeLauro have introduced Johanna's Law, which is co-sponsored by many members of this committee. In fact, there are 220 co-sponsors of this important piece of legislation. Under Johanna's Law, the Department of Health and Human Services (HHS) would conduct public education and awareness programs to explain the facts about the early warning signs of gynecologic cancers to the women of this country. The activities HHS would undertake would include various forms of communication (written materials, public service announcements and more), as well as outreach in cooperation with nonprofit organizations. Johanna's Law would entail modest levels of funding (\$15 million annually), but these monies would be significant in our fight to end cancer as a threat to women. I cannot over-stress the importance of arming women with the basic facts about these cancers. It is our front line defense in the battle against these killers of women.

An ad calling attention to "Johanna's Law" appeared today in "Roll Call" through a generous donation from Angelina Jolie. Maybe you saw it. It portrays a woman alone, sitting on an examination table with a look on her face of overwhelming sadness. The caption reads, "If only she had known sooner." I believe that no woman should have to face a diagnosis of gynecologic cancer because she did not know the risk factors and symptoms. This is the purpose of "Johanna's Law.

I look forward to answering your questions and thank you for the opportunity to testify today. I am constantly inspired and humbled by the strength and determination of women to live. I believe your leadership on this issue will give even more women the full lives they so richly deserve. Thank you.